

Aging with Disability: Demographic, Social, and Policy Considerations:
May 18, 2012

Bridging network divides: Building capacity to support aging with disability populations (& rethinking outcomes) in LTSS

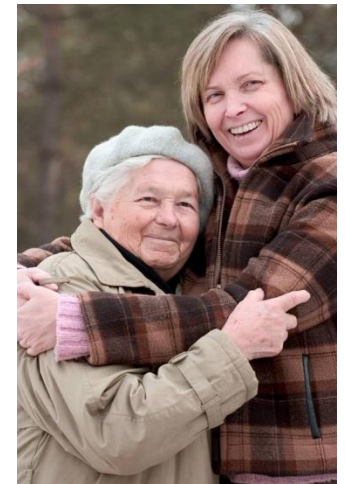
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Presentation agenda

- ▶ The need to building capacity in LTSS to serve persons aging with disability.
- ▶ Foundations for building bridges across aging and disability service systems.
- ▶ Balancing directives as levers for bridging aging and disability LTSS.
- ▶ Using Re-balancing initiatives to facilitate research related to capacity building and bridging.
 - Understand met and unmet need
- ▶ Building bridges on common ground: Rethinking outcome measures.

Central questions

- ▶ Is aging *with* disability different than aging *into* disability?
- ▶ If so, or if not, so *what*? What does this mean for LTSS?



Examples:

- ▶ Lily, a physically healthy, but depressed, 67-year-old woman who was born with blindness has early onset of dementia. Lily developed exquisite way-finding abilities over her life but now is losing her primary disability adaptation skills.
 - How can Lily best be supported to help her remain living in the community?
- ▶ Rob, a 65-year-old man with spinal cord injuries and quadriplegia, is losing his daily Personal Attendant Services (PAS) provided through vocational rehabilitation services for employment seekers. He has a small support network, but cannot replace the PAS with informal or privately paid for care.
 - How can Rob avoid nursing home placement?
- ▶ Uma, a woman with developmental disabilities, age 62, would like to live alone in her own apartment for the first time. Her parents recently passed away and she is retiring from working at a sheltered workshop.
 - What resources are available to build Uma's social network and help her live independently?

Aging with disability LTSS capacity questions:

- ▶ Where do Lily, Rob & Uma go to seek assistance with their LTSS needs?
- ▶ What LTSS are available to them?
- ▶ Who is trained to help them?
- ▶ Will they be able to access existing LTSS?
- ▶ Will their needs be adequately addressed with existing LTSS and within existing service delivery systems?

Why is there a need to build capacity in LTSS for persons aging with disability?

- ▶ Historical segmentation of aging and disability populations, programs, and LTSS networks.
- ▶ Distinct fields of knowledge and practice, limited sharing or exchange.
 - Limited specialty knowledge – e.g. “*aging with*” .
- ▶ Growth of aging with disability populations.
- ▶ *Olmsted* decision & New Freedom Initiative: Re-balancing programs change LTSS landscapes.
- ▶ We don't know what we don't know.
 - Concerns about assumptions we make.

Understanding met & unmet need for LTSS among persons aging with disability

- ▶ Limited knowledge of existing capacity to serve persons aging with disability within aging or disability LTSS networks.
- ▶ Ongoing professional discourse about approach.
 - Build aging capacity within disability?
 - Or build disability capacity within aging?
- ▶ Unclear extent of met and unmet need:
 - Limited knowledge about size of population.
 - Uncertain how met/unmet need transitions across disability & aging systems.
 - However, enough evidence to support hypothesis of different experiences negotiating disability and care and support needs.
 - Clear need to build new and more knowledge and engage in knowledge transfer and exchange.

Examples of Differences in LTSS needs

- ▶ Aging of parental caregivers and the need for transition planning for persons with developmental disability (Hewitt et al., 2010), traumatic brain injury (Minnes, Woodford, Carlson, Johnston, & McColl, 2010) and persistent mental illness (Chen, 2008).
- ▶ Considerations of over-use injuries and prevention of secondary conditions in health promotion interventions for individuals with spinal cord injuries (Rimmer, 2005).
- ▶ Need for better prevention, intervention and treatment of elder abuse (including physical, sexual, and financial) among older adults with developmental disability (Ansello & O'Neill, 2010).
- ▶ Need for age-specific services and treatments for persons with aging with severe mental illness (Cummings & Kropf, 2011).

Building capacity among professional LTSS providers - policy implementers

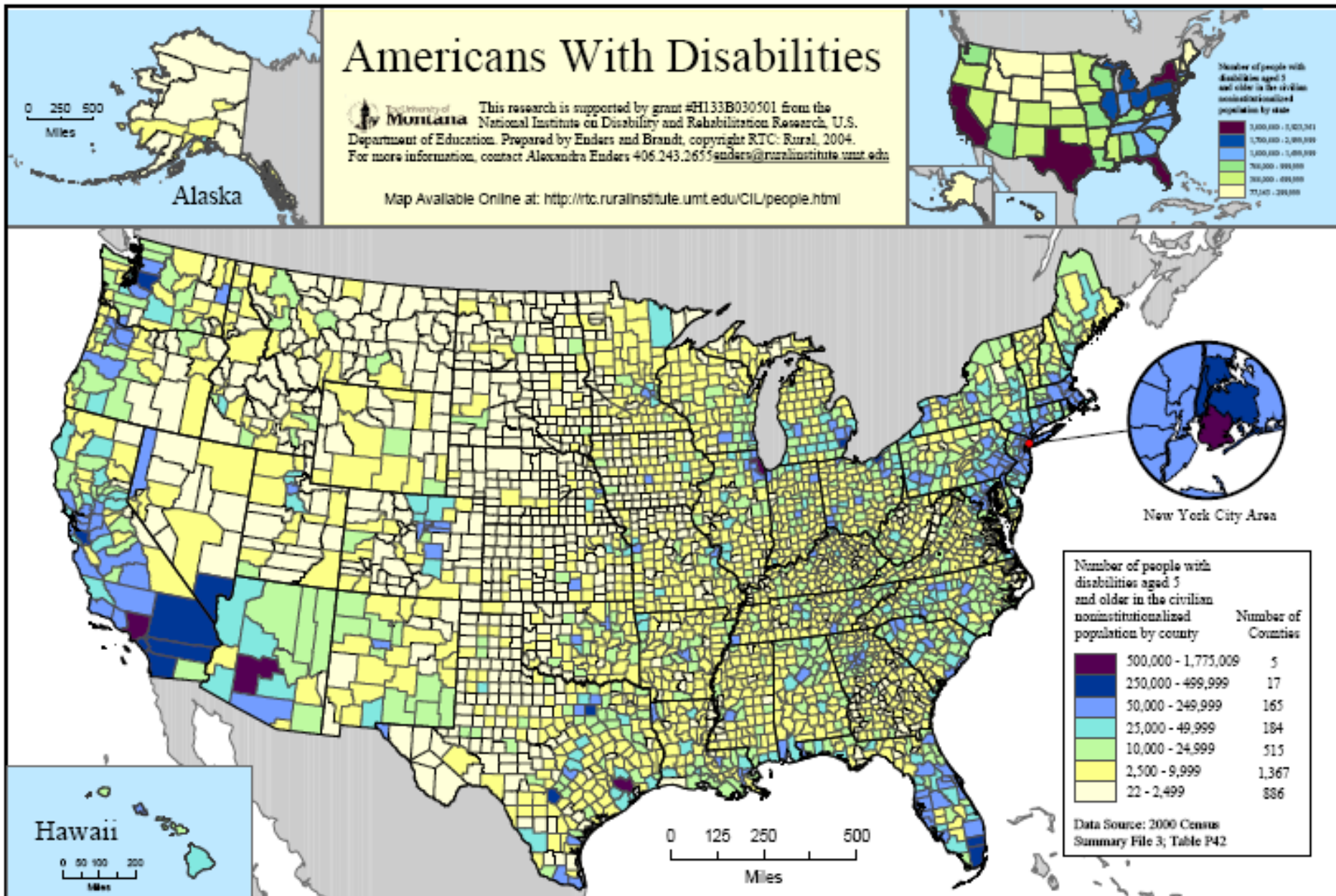
Administration for Community Living		
Administration on Aging	Administration on Developmental Disabilities	Office of Disability
<ul style="list-style-type: none"> • 56 State Units on Aging • 629 Area Agencies on Aging • 244 Tribal Organizations • 2 Native Hawaiian Organizations 	<ul style="list-style-type: none"> • 55 State Councils on Disability • 57 State Protection & Advocacy Systems • 67 University Centers for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) 	<ul style="list-style-type: none"> • Partnerships with Health & Human Services agencies, federal departments and offices, state offices, national organizations, constituents providers, advocacy and persons with disabilities

County aging & disability units

400+ Centers for Independent Living

State Medicaid offices

Private & Not-for profit LTSS providers



Foundations for bridging aging and disability & defining bridging

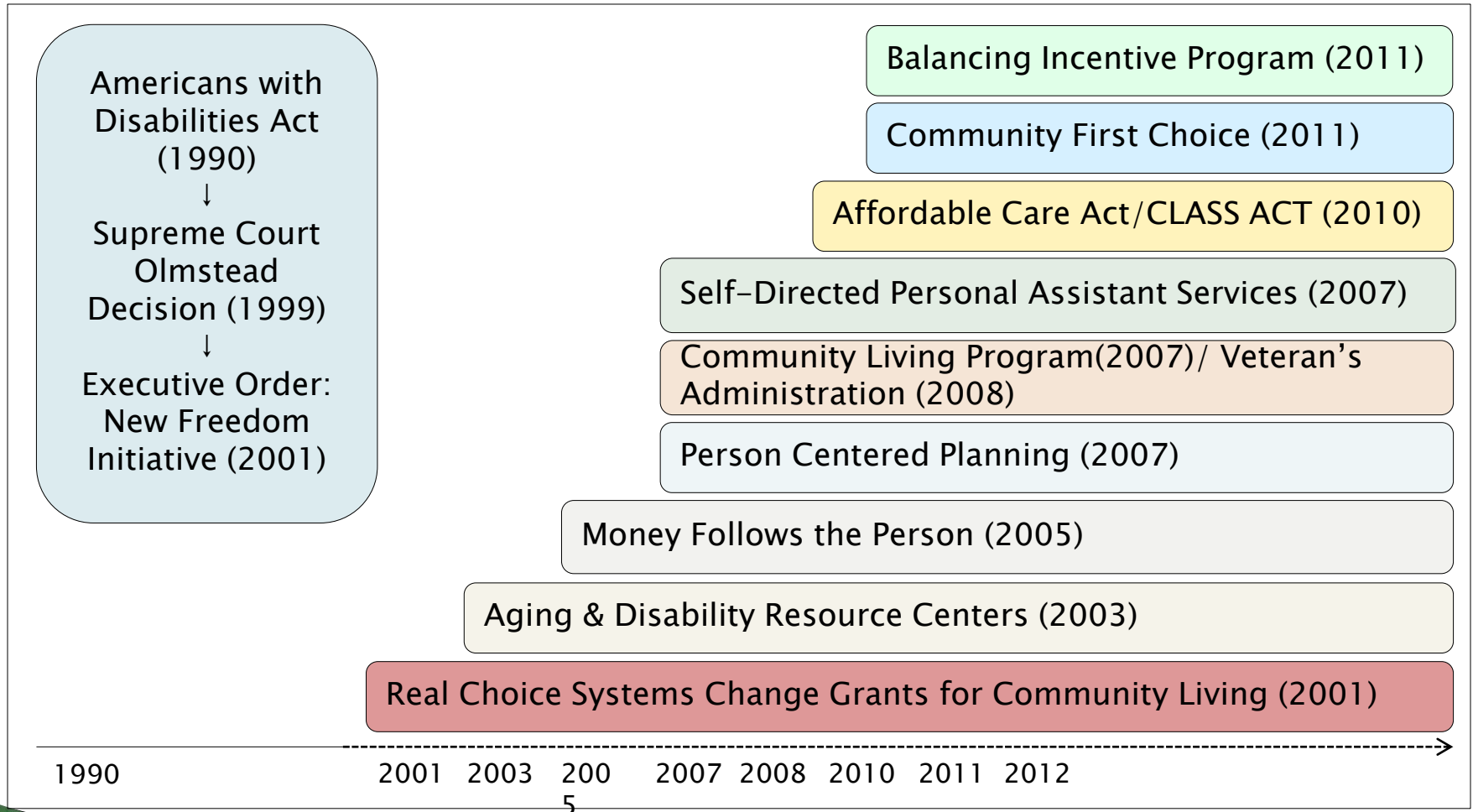
- 40+ year history of bridging work in the U.S.
- *Toronto Declaration on Bridging Knowledge, Policy & Practice in Aging and Disability (March 30, 2012):*

Bridging encompasses a range of concepts, tasks, technologies and practices aimed at improving knowledge sharing and collaboration across stakeholders, organizations and fields of care and support for persons with disabilities, their families, and the aging population.

Bridging tasks include activities of dissemination, coordination, assessment, empowerment, service delivery, management, financing and policy.

The overall purpose of bridging is to improve efficiency, equity of care, inclusion and support at all levels, from the person to the society. It is also an issue of recognition of the complexity of the human condition from birth to death, the capabilities of all people, and the need for a conceptual vision that takes into consideration planning for a society where participation of all citizens as the ultimate goal. (Bickenbach et al., 2012, page 2).

Leverage for Bridging: LTSS Rebalancing



From policy window to research opportunity: in support of capacity building & bridging

► Applied bridging example:

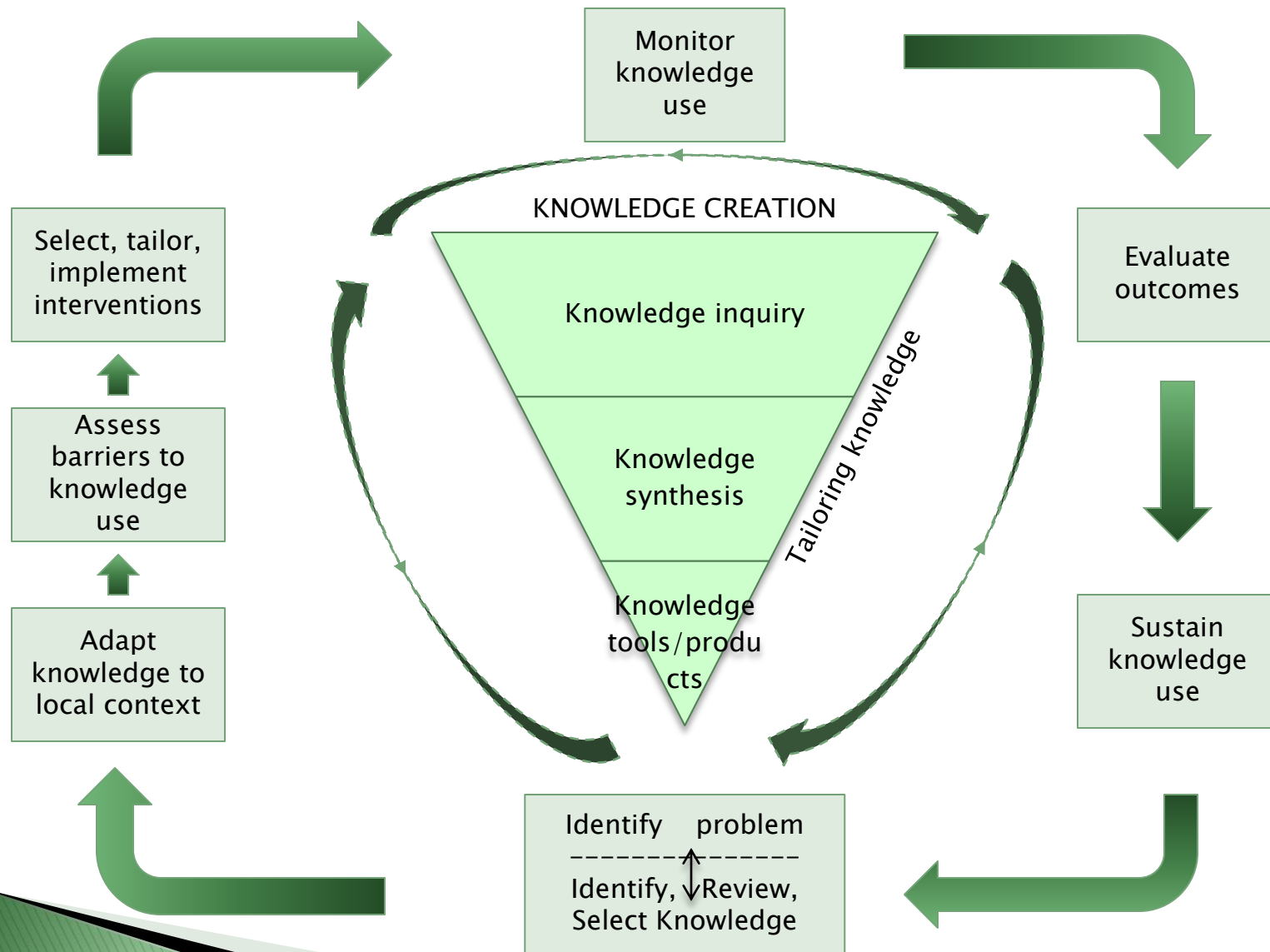
- **Aging & Disability Resource Centers (ADRCs):** Coordinated entry points into LTSS, negotiate critical pathways, and more.
- **Money Follows the Person (MFP):** Medicaid funds follow person from institutional to HCBS.
- **Community Living Program (CLP):** Supports finding HCBS before spend down to Medicaid levels.
- **Lifespan Respite Care Program (LRCP):** Coordinates respite care information, training across populations.

Bridging activities within Re-balancing Initiatives

Bridging activities (Identified by Toronto Decl.)	ADRC	MFP	CLP	LRCP
Assessment: Shared or universal need assessment protocols	X	X	X	*
Coordination: Shared consumer databases and/or linked information technology infrastructure	X	X	X	*
Empowerment: Promotion of consumer-directed services and/or inclusion of consumer & family stakeholders in program operations	X	X	X	X
Dissemination: Use of technical assistance exchanges and/or shared messaging to consumers	X	X	X	X
Service delivery: Shared information & referral databases and/or transition protocols between care settings	X	X	X	X
Management: Shared leadership, and/or inclusion of aging and disability stakeholders, and/or program and operational transparency	X	X	X	X
Financing: Coordinated funding and/or streamlined consumer eligibility	X	X	X	*
Policy: Formal linkages between aging and disability entities in program design	X	X	X	*

Note: X=Activities found within program evaluation reports. *=Activities identified in program summaries but not in program guidelines.

Capacity building within “Knowledge to action process”



Example of research potential of Rebalancing programs to facilitate capacity building and bridging knowledge: caregiving

Bridging activities	Capacity building potential	Evaluate of bridging mechanisms
Assessment: Shared or universal need assessment protocols	<ul style="list-style-type: none"> - Collect data on specific aging with disability caregiving issues - Identify unique and met and unmet needs among aging with disability populations 	<ul style="list-style-type: none"> - Creation, adoption & use of universal protocol across networks, organizations, and practitioners - Pros and cons of universal instrumentation
Coordination: Shared consumer databases and/or linked information technology infrastructure	<ul style="list-style-type: none"> - Assess variances in type and amount of supports provided between caregivers of persons aging with and aging into disability - Understand patterns of service use 	<ul style="list-style-type: none"> - Assess capacity of shared databases to identify met & unmet need - Assess organization capability participate in linked IT systems
Management: Shared leadership, and/or inclusion of aging and disability stakeholders, and/or program and operational transparency	<ul style="list-style-type: none"> - Engaging caregivers of persons aging with disabilities in respite program development, implementation, & evaluation 	<ul style="list-style-type: none"> - Assess use of stakeholder engagement models - Access effectiveness of models to improve programs

Why take this approach?

- ▶ Capitalizing on Re-balancing initiatives that links OAA, Medicaid, VA and other LTSS programs presents new research opportunities, venues for knowledge transfer and exchange.
- ▶ Umbrella for research, practice & policy questions including:
 - What evidence-based practices are transferrable between aging and disability fields?
 - What “general” professional practices are appropriate and/or useful?
 - What training/education is needed?
 - Is it better to collaborate across aging and disability or to build capacity within aging or disability? Or both?
 - What are the roles of consumers? Other stakeholders?
 - What are the best (most meaningful) outcomes to measure?

Building bridges on common ground

- ▶ Long standing difficulty in bringing aging and disability sides together for common cause:
 - New common ground – *community living*.
- ▶ Assessing community living outcomes presents an opportunity to measure the benefit component of the cost-benefit equation of HCBS.
 - Understand the *investment* in people with disabilities of all ages and their families.
- ▶ A long way to travel:
 - Trust, turf, existing investments, openness to new populations, knowledge, skills, addressing discrimination.

Bridging is challenging, but capacity building is crucial.

- ▶ Rebalancing initiatives are delicately perched in many states.
 - Rebalancing incentives leverage change with modest funds – but have difficulty dislodging cultural norms & values.
- ▶ Aging with disability populations are in need of LTSS assistance.
 - Existing knowledge and training offers some, but limited support for practice professionals and programs to draw on.
- ▶ Aging with disability populations are growing older, regardless of our state of ready.
 - The Older Americans Act has universal eligibility*.

*Policy Ace

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